Follow-up assessment of high-risk newborns in Switzerland

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Recommendations of the Swiss Society of Neonatology, the Swiss Society of Developmental Pediatrics and the Swiss Society of Neuropediatrics

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Introduction

Target population

High-risk newborns in the context of these guidelines are children who were born very preterm (before 32 weeks gestational age) or children who developed a hypoxic ischaemic encephalopathy (Sarnat grade 2-3) during the first hours of life.

Background

In recent decades, technical advances and improved medical treatment have resulted in better perinatal care, leading to significantly higher survival rates in high-risk newborns.

Simultaneously, changing demographics such as older maternal age and higher rates of medically assisted reproductions have led to a higher rate of infants born preterm.[1] In Switzerland, the rate of children born with a birth weight below 1500g has doubled over the last three decades.[2] Approximately 800 preterm infants (with a gestational age below 32 weeks) are born in Switzerland every year.[3] While the rate

of children born preterm has steadily increased, the rate of children who are born at term with a moderate or severe encephalopathy due to perinatal asphyxia (hypoxic-ischemic encephalopathy, HIE) has remained relatively stable at 1 per 1000 births.[4] Accordingly, approximately 80 infants per year are born in Switzerland with moderate to severe encephalopathy (Sarnat grade 2-3)[5] due to perinatal asphyxia during the first hours of life.

In both populations, about 15% of the children die at or soon after birth,[6,7] a rate comparable to or lower than that of at-risk populations in other nations with similar health care standards.[8] Of the surviving infants, approximately 10-15% develop a severe disability such as cerebral palsy, mental retardation, or severe sensory impairment.[9,10]

The prevalence of major developmental disabilities increases with more severe degree of HIE or lower gestational age at birth. Importantly, moderate to mild neurodevelopmental disorders can also occur in the absence of major disabilities in all developmental domains, including learning disabilities, language delay, motor coordination disorder, and problems of behavior and social interaction. Some problems, such as dyscalculia or executive function impairment, only become apparent during later school age, when more complex academic and cognitive skills develop[11],[12],[13]. Overall, these problems occur in approximately 50% of children with HIE Sarnat grade 2-3[14] or in 30-50% of children born below 32 weeks of gestation.[15]

Interestingly, at least in children born preterm, health-related quality of life is comparable to that of their peers.[16,17] Regarding long-term outcomes, the prevalence of neurodevelopmental deficits varies greatly depending on country and the sociodemographic background of the study populations. [18,19] Many preterm survivors, however, are in mainstream school and are coping well as they enter adult life, although some will continue to need additional health, educational, and social services.[20] Currently, no study has examined long-term or adult outcome after perinatal asphyxia. The degree to which perceived improvements between school age and adult age are a result of early intervention strategies, [21]an optimal schooling system, or delayed maturational processes remains unclear.

The Swiss network contributes to answering this question. Importantly, early detection of a developmental problem is critical for caretakers, parents, and the growing child. We conclude that high-risk newborn children in Switzerland require repeat, standardized and detailed follow-up examination at specialized centers, both to assist in their development and to answer important research questions.

SwissNeoNet

In 2002, all nine Swiss perinatal centers that combine neonatal with developmental- and/or neuropediatric units (Geneva, Lausanne, Berne, Basel, Aarau, Lucerne, Chur, Zurich and St. Gallen) funded the Swiss Neonatal Network & Follow-up Group (SwissNeoNet) to coordinate reporting of mortality, morbidity, and neurodevelopmental outcome of high-risk newborns. The aim was to provide continuous follow-up assessments of high-risk newborns across Switzerland so as to improve the quality and efficiency of medical care through a nationwide follow-up network.. These assessments complement the regular follow-up assessments performed by primary care providers. To ensure high follow-up rates, additional regional follow-up centers (Bellinzona, Lugano, Münsterlingen, Winterthur, Fribourg, Bienne and Neuchatel) were integrated into the network.

A state-of-the-art population-based online registry for high-risk newborns in Switzerland supports the network's administration and provides a foundation for its dual purpose in research and quality control. The most important diagnoses and treatments are prospectively collected during the first perinatal hospitalization, and standardized follow-up assessments are undertaken at two and five to six years of age.

Today, this registry holds continuous standardized population-based data for very preterm born infants since 2000 and for term infants with HIE since 2010.[22]

Purpose of the follow-up examinations of high-risk newborns in Switzerland

The purpose of follow-up assessments within the SwissNeoNet is to provide early detection of neurodevelopmental impairments in high-risk children using standardized assessment tools. This enables early treatment of developmental impairments and facilitates parental counseling.[18,23,24] By registering neurodevelopmental outcome within the SwissNeoNet, epidemiological data is gathered which allow for nationwide, population-based information on outcome in both at-risk populations.

The present paper summarizes the standards for follow-up assessments elaborated in Switzerland since 2006 by experienced follow-up specialists and child neurologists. These standards were drawn from biannual structured and minuted network meetings of the SwissNeoNet. They document a consensus in Switzerland on how to optimally perform follow-up assessments in high-risk newborn infants. They, however, also respect regional differences and describe purpose, location, content, follow-up ages, and recruiting strategies.

The Swiss level III neonatology units initiated a quality network that covers more than 95% of Swiss newborn infants born below 32 weeks GA and/or <1500 g on a voluntary basis and without government funding. Since 2010, term infants with HIE are also included in the register.
This network monitors the most important outcome variables, relates them to neonatal care, and compares them between units, activities which enable the detection of potential areas of improvement.[8] Further, the Swiss population outcomes are regularly compared with published reports from other networks such as the Vermont Oxford Network[25] and the EuroNeoNet[26]; this reveals that Switzerland has a high international standard in neonatal care.
So far, these international comparisons have been restricted to outcome data at discharge. The success of continuous progress in perinatal medicine is often monitored by means of short-term outcomes. They may, however, result in long-term disabilities. One notable example of the contrast between short- and long-term benefits arose from postnatal dexamethasone treatment, facilitating extubation in very preterm infants; however, the use of dexamethasone was later associated with an increased risk of cerebral palsy.[24] Thus, the epidemiological monitoring of long-term outcome measures is essential.

The data monitoring and center-to-center comparisons depend on the completeness of data at a population level and on their comparability between units, i.e. that all units use comparable test batteries at similar time intervals. In addition, the definitions of morbidities and impairments (such as moderate to severe auditory or visual impairment) need to match published international standards to allow comparison of Swiss data to international data. Finally, these definitions need to incorporate regional language differences and local follow-up standards.

To improve neonatal care and outcome of future high-risk newborns, data from follow-up assessments are continuously and prospectively collected in the registry and linked to neonatal data, which is collected from birth until discharge. In this way, the register provides an invaluable tool for pinpointing risk factors for developmental impairment. Furthermore, the administrative support of the registry can aid follow-up recruitment and organization, which increases the follow-up rate, to the benefit of each participating center and ultimately of the children.

Several research studies from the registry have contributed to a better understanding of risk factors for adverse outcome. For example, Schlapbach et al. demonstrated that neonatal sepsis is significantly associated with impaired neurodevelopmental outcome at two years of age in extremely preterm.[27] Another important finding of the collaborative effort between neonatologists and developmental pediatricians is that neurodevelopmental outcome of extremely preterm born children is determined by major neonatal morbidities rather than gestational age or birth weight.[9] These findings have a direct impact on parental counseling and the medical decision-making processes.

Several obstacles may impair communication between the neonatal units and the follow-up centers. Each high-risk newborn needs an individual invitation to a follow-up center. However, follow-up centers are not always made aware of the existence of a patient, or the patient is not transferred to the correct center. This often happens when young families move to settle at a more permanent location before or at the time when their children start school. To avoid the subsequent loss to follow-up, the registry's infrastructure provides follow-up units with a constantly updated list from which the units can see who needs follow-up. If a patient has moved to the catchment area of another unit, the registry acts as a broker between the old and the new unit so that the new unit has the information it requires to invite the patient. Should a patient be unknown to a follow-up unit because the unit has never received a referral, the registry provides the details of the neonatal unit that formerly treated the patient and can perform the formal transfer. In each case, the registry itself does not obtain any personal information other than the birth date and the birth location, from which it cannot derive any identification. These actions greatly reduce loss of follow-up.

One could argue that better discipline in communicating among participating units would be sufficient and would render organizational assistance unnecessary. However, as personnel such as residents or part-time administrative assistants in participating units frequently change, even the best efforts at improving discipline are likely to fail. This is why we chose to follow the recommendation of quality improvement experts such as Ellsbury et al. and invested in a functioning system rather than tinkering with best efforts.[28]

One consequence, however, is that these recruiting lists sometimes lead to the misconception that follow-up assessments are performed 'because of the registry' or even 'for the registry'. This is not the case, so it is important to state that the registry's first and foremost goal is to facilitate follow-up assessments for the **benefit of the child and its parents**. The data collection to the registry itself is of secondary importance and is dependent upon parental consent, even if it will additionally benefit the population of high-risk newborns as discussed above. None of the children are recruited simply or primarily for the purpose of delivering data to the registry.

Location of follow-up examinations

Children born at high risk for developmental impairment are examined in a limited number of centers (Table 1). These centers are specialized and experienced in developmental assessments and use validated and standardized tests and questionnaires. The centers are either child development or pediatric neurology centers. Pediatricians in private practice can examine high-risk children for the registry instead of a center if they can demonstrate comparable experience and training specific to high-risk newborn infants and if they frequently use the test batteries agreed upon by the network. All participating centers and pediatricians need to be members of the Swiss Neonatal Network & Follow-up Group and participate at the regular, biannual conferences. They enter the standardized data they have acquired into the registry as specified below.

Table 1: Developmental pediatric and neuropediatric units in Switzerland performing neurodevelopmental follow-up of high-risk newborns

Location	Address	Telephone
Aarau	Neuropädiatrie, Klinik für Kinder und Jugendliche, Kantonsspital Aarau (KSA)	*062 838 49 17*
Basel	Abteilung für Neuropädiatrie, Universitätskinderspital Basel (UKBB)	*061 704 19 06*
Bern	Abteilung für Neuropädiatrie, Universitätsklinik für Kinderheilkunde Inselspital	*031 632 31 10*
Biel / Bienne	Zentrum für Entwicklungsförderung (Z.E.N), Kloosweg 22, Biel	*032 321 42 00*
Chur	Neuropädiatrie, Kantonsspital Graubünden (KSGR)	*081 256 64 06*
Fribourg	Neuropédiatrie, Clinique de pédiatrie Fribourg (HFR)	*026 426 74 17*
Genève	Service du Développement et Croissance, Département de l'Enfant et de L'Adolescent, Hôpitaux Universitaires de Genève	*022 372 54 91*
Lausanne	Unité de Développement, Centre hospitalier Universitaire Vaudois (CHUV)	*021 314 34 69*
Luzern	Abteilung für Neuropädiatrie, Kinderspital Luzern	*041 205 31 70*
Neuchâtel	Département de Pédiatrie, Hôpital Neuchâtelois	*032 713 34 64*
St. Gallen	KER-Zentrum, Zentrum für Kinderneurologie, Entwicklung und Rehabilitation, St. Gallen	*071 243 73 32*
Thurgau	Entwicklungspädiatrisches Zentrum, Kantonsspital Münsterlingen (KSM)	*071 686 21 65*
Ticino	Servizio di Neuropediatria, Ospedale Regionale di Bellinzona	*091 811 91 95*
Valais	Service de Pédiatrie, Hôpital de Sion	*027 603 41 68*

Winterthur	Sozialpädiatrisches Zentrum, Kantonsspital Winterthur	*052 266 29 17*
Zürich	Abteilung Entwicklungspädiatrie, Kinderspital Zürich	*044 266 82 47*

Contents and milestone ages of follow-up examinations

The individual follow-up examinations are performed at intervals defined by each center but covering the jointly agreed cornerstone ages. Correction for prematurity is made until the completion of the two-year examination.

Up to two years, the age at which follow-up examinations are performed depend on the local tradition of follow-up intervals, available personnel and the regional reimbursement practices of the disability insurance company (IV). At **2 and 5-6 years**, follow-up examinations using the jointly agreed identical assessment batteries are uniformly performed throughout Switzerland to ensure comparability (Fig. 1). According to Vohr et al. (2003), a valid developmental examination combined with a neurological examination conducted at 18-22 months corrected age will identify the vast majority of children with cerebral palsy (CP), certainly all those with moderate or severe CP.[24] In addition, cognitive and language delay should be assessed at that age, if not already diagnosed by the primary care provider, and a special evaluation by a speech and language therapist can be initiated so as to guarantee appropriate treatment. In the case of a cognitive delay, early intervention therapy should be started. If behavioral or social interaction problems are noted during this exam, or if it is unclear whether a developmental delay is present, specialists will re-examine these children for further testing or refer children to a child psychologist.
At 5-6 years of age, the evaluation provides valuable information on a wide range of developmental domains that will help to determine the issue of school readiness, among other questions. Currently, this assessment milestone suffers from the difficulty of long-term tracking and high loss to follow-up associated in part with long periods of lack of contact with the parents. Some centers may therefore assess the children at 3-4 years using their individual assessment protocol.

The test batteries chosen by the center representatives of the SwissNeoNet for the two milestone ages of 2 and 5-6 years are standardized, internationally used assessment tools with normative values.[29,30,31] Their use will allow us to compare outcome results with those of other centers.

At 18-24 months corrected age (maximum age range 15-29 months)

- Bayley Scales of Infant Development III (Cognition, Language, Motor)[32] for all children born with a gestational age below 28 weeks or for all children that developed a moderate to severe encephalopathy due to asphyxia (Fig. 1). For all other children, the Griffith's Test[33] may be administered if the Bayley Scales of Infant Development III are not available or in case of time constraints.
- Neurological examination including classification of cerebral palsy according to Surveillance of Cerebral Palsy in Europe (SCPE)[34] and Palisano's gross motor function classification[35]
- Visual examination (incl. Lang test)[36] :classification into
    - normal development (no problems or minor problems not interfering with function)
    - moderate problems (e.g. corrective glasses, strabism)
    - severe problems (severe visual impairment or blindness)
- Hearing examination to allow classification into
    - normal development (none or minor problem)
    - moderate (moderate hearing impairment not requiring hearing aids)
    - severe (hearing aids or cochlear implant)

At 5 – 6 years <u>uncorrected</u> age (maximum age range 4.5 – 6.5 years)

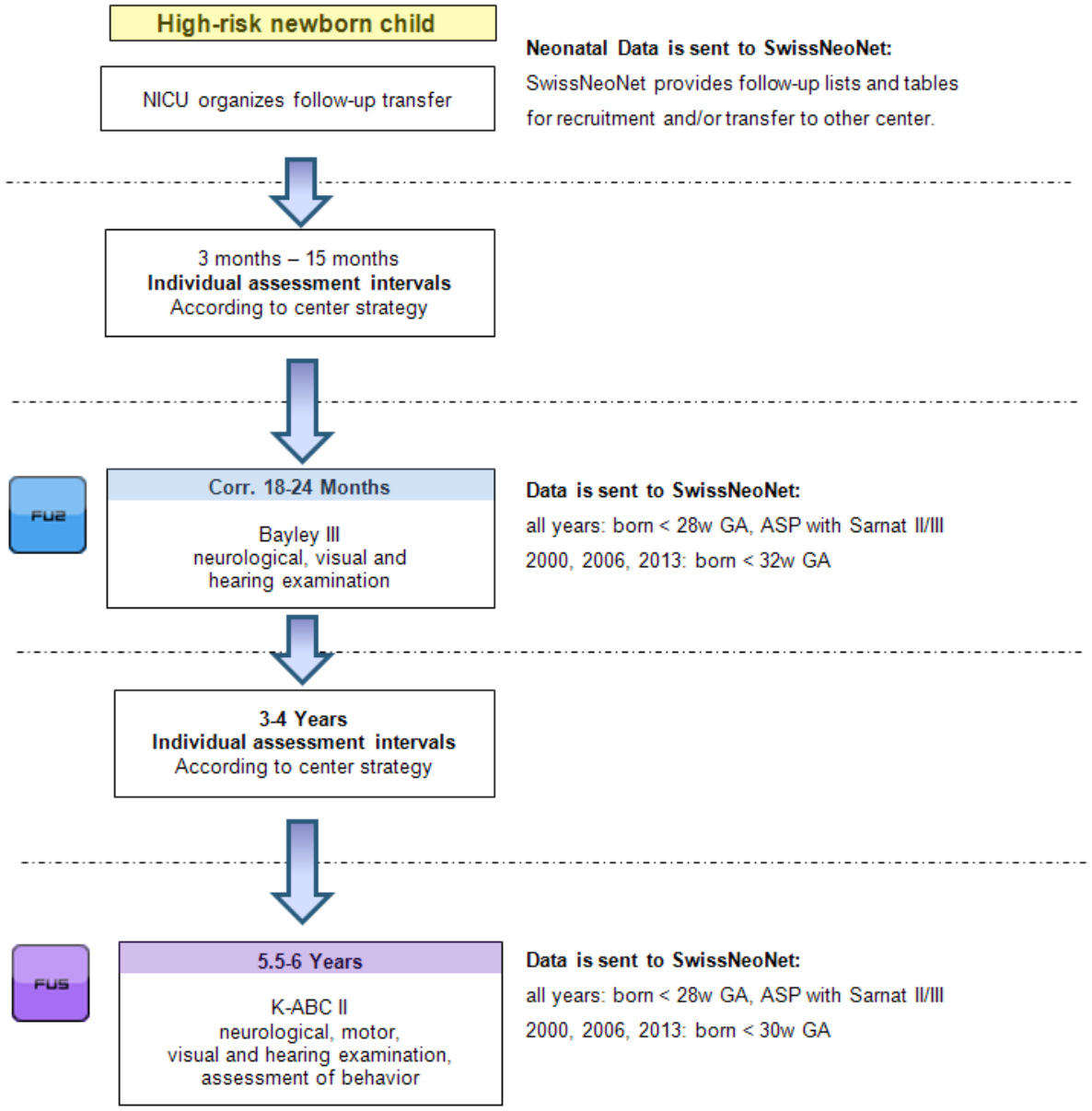
- Intellectual examination: Kaufmann Assessment Battery for Children (K-ABC)[37*]
- Neurological examination: this includes CP classification according to SCPE and the gross motor function classification system[35]
- Motor examination: Zurcher Neuromotor Assessment [38]

[*] The currently used developmental test at 5-6 years of age, i.e. the K-ABC, is outdated. While its revised version (K-ABC II) is applied in English- and French-speaking nations, a German version is not yet available. The SwissNeoNet representatives have therefore decided to wait until 2015 before selecting a replacement assessment battery for K-ABC, which must be available for all three major Swiss languages.

- Assessment of behavior: Strength and Difficulties Questionnaire (SDQ)[39]
- Visual examination: classification into
    - normal development (no problems or minor problems not interfering with function)
    - moderate problems (reduced vision despite correction)
    - severe problems (severe visual impairment or blindness)
- Hearing examination: classification into
    - normal development (none or minor problem)
    - moderate (moderate hearing impairment requiring hearing aids)
    - severe (hearing impairment despite hearing aids)

To obtain outcome data comparable with published data, the participating centers must reach a follow-up rate of at least 80% both for the two-year and for the 5-6 year examination according to the Standards for Levels of Neonatal Care of the Swiss Society of Neonatology[40] and to international recommendations.[24]

Fig. 1: The ages at which information on outcome is collected for the SwissNeoNet



Avoiding loss of follow-up

The online registry of the SwissNeoNet provides lists and tables of eligible children ensuring that no high-risk child is forgotten. Support tools for follow-up include alerts to send invitations to parents for follow-up consultations, administrative transfer of children from one perinatal center to another, calculation of corrected age and the provision of contact information on partnering institutions. Access to the registry is restricted to the attending physicians and therapists of the participating centers. Children can be identified via their encrypted personalized data only by the attending physician or therapist. Parents of children not yet covered by the follow-up program

are invited to contact the follow-up center closest to home for enrollment, as listed in Tab. 1.

In addition to the data collection and management tools, the network fosters transparent multi-center research and quality control projects to maximize the benefit of maintaining an elaborate database by initiating studies, offering coordination and/or statistical support, fostering collaboration between participants, etc.

To ensure the highest follow-up rate, we recommend these steps :

- Families must be made aware of the importance of follow-up examinations during the first hospitalization after birth, i.e. by the neonatologists. Neonatologists must either arrange the first follow-up examination directly or send a copy of the discharge report to the follow-up center nearest to the family's home (Tab. 1).
- Establishment of first contact between the follow-up center and the families should be via a secretary or a physician
- This contact should be complemented by a written invitation
- Twins/triplets should be invited simultaneously if resources allow
- If parents refuse assessment or parents do not show up, then the pediatrician responsible should be informed so that he or she can contact the parents directly and inform them of the purpose of the examinations.
- If parents continue to refuse to attend examinations, they should be asked if they would be willing to fill in a parental questionnaire that would benefit the research and quality control but would be of no direct benefit to the child or its family.

Additional information

Additional information can be found on the website of the Swiss Society of Neonatology under “Network”: www.neonet.ch

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